issue no. 7

childAIDS

NEWSLETTER OF THE NATIONAL FORUM ON AIDS AND CHILDREN 1995 issn 0969-4048

Issues for African children affected by HIV/AIDS

by Josephine Namusisi, Blackliners

Statistics show that in London the majority of children infected and affected by HIV/AIDS are of African parentage and especially from East and Central Africa. At St. George's Hospital in south London for instance, 80% of the children attending the HIV clinic are of East African parentage.

This article is intended to share and highlight some of the major social and political issues specifically affecting African children and to make recommendations. It should be noted however, that children's issues cannot be looked at in isolation from their families.

Conflict between African and British beliefs and value systems

African children are brought up with different beliefs and values from those in this country. It is likely that children will be getting different messages at home and in outside institutions, such as schools and hospitals. For example, a child attending school will be told that it is respectful to look at someone in the face while talking to them, whereas this is considered rude and disrespectful at home. This is just one example, but these conflicting messages are a fundamental reason why African children have difficulty in adjusting to British systems.

In African societies emphasis is put on the family, while in this country it is put on the individual. Adult members of the family make all the important decisions for the family in death, conflict, illness, and so on. For example, if there has been violence in the family by one of its members, a family or clan meeting is called to decide what action has to be taken and what punishment should be handed out. In similar circumstances in Britain, where the emphasis is put on the individual, other institutions like social services, the law, and the police take over.

The effect of war and violence

The majority of African families in the UK affected by HIV are asylum seekers and refugees. They and their children have fled from traumatic experiences of torture and killing, as seen for example in Rwanda. Children who have survived wars and suffered such traumatic experiences will have developed coping mechanisms for survival. In most African countries, there is no individual care and support for victims of these circumstances simply because everyone is going through the same experience and the emphasis is still on communal survival. When individual care is introduced it is not only difficult to accept but it opens up painful past experiences and so when working with African children, workers should be aware that there are other traumatic experiences apart from HIV.

Medical care versus traditional medicine

Apart from fear and lack of trust of the British system stemming from immigration issues, African families still believe in traditional religion and medicine. This has implications for children who may be presented late for services. As with other diseases there are many traditional remedies for minor and serious ailments. Sometimes families will combine both traditional and conventional medicine. Furthermore, the stigma attached to HIV/AIDS means that families will not access services in case confidentiality is broken. As a result of all this, African children may not benefit much from available treatment, at least not initially.

Related to this is the issue of drug trials. There has been much publicity about what benefit, if any, children get from these trials. Because many positive children or those born to HIV positive mothers are put on these trials, some parents are unwilling to access health care in fear that the same will happen to their children. A common complaint from parents is that they are put or feel under pressure to accept drug trials for their children.

Children's support

As already mentioned, African children come from complex social, economical and cultural backgrounds, with totally different belief and value systems in their upbringing from those in this country. This means that the approach used to support children in this country cannot be readily applied to African children. For example counselling a child from a refugee family who is faced with the prospect of losing her parent(s), and maybe her only security, requires a different and specialised approach with careful planning and back up services. This child may never have had to talk about her fears and experiences with anyone, let alone a stranger, and was brought up in a culture which does not believe in consulting with children especially on major issues.

Children in the African family

Children are loved and cherished in the African family but these emotions are rarely shown. There is also a belief that if you let a young tree bend and fail to straighten it at the early stage, you will never be able to straighten it later or if you try, you will break it. Punishment is given to children when they are naughty to make sure that they grow into good and respectful adults. All decisions including punishment are made by adult members of the family. Children are protected from matters of importance or grave worry. For example, a child will not be consulted about who she wants to live with when her parents die. The family clan will decide who is most able and appropriate to raise that child, based on the needs of that child.

Responsibility of any sort is bestowed upon children as they grow up and that is why there are initiation ceremonies in many African tribes to welcome adulthood. Many times, children have to earn their trust in the

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childAIDS

ChildAIDS is the quarterly newsletter of the National Forum on AIDS and Children. The Forum aims to promote the interests of children and young people infected or otherwise affected by HIV, and brings together more than 70 organisations concerned with children and HIV, from health, social services, education and the voluntary sector.

Views expressed in the newsletter do not necessarily reflect those of the Forum as a whole.

Contributions of articles, letters and materials for review are welcomed and should be sent to the editor, Neil Orr, at the following address:

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forum news

National Forum on AIDS and Children: 1994/95 report

1994/95 was a very productive year for the Forum, and included the following activities:

Meetings: Forum meetings continued to provide an opportunity for the sharing of experience and good practice, and for people to hear about the latest developments in services and research. More than 150 people attended our three meetings in 1994/95: **Developing respite care services for children and families affected by HIV/AIDS**, May 1994, London; **Drug use and HIV: meeting the needs of children and families**, October 1994, George House Trust, Manchester; **Children and HIV: a closer look**, March 1995, London.

In addition the World AIDS Day conference **Planning HIV services for children and families - looking to the future** organised by the Forum with the National Children's Bureau and the National AIDS Trust, brought together 135 people to consider the future shape of HIV services for children and families affected by HIV in the UK.

Policy work: The Forum represented the interests of children affected by HIV to various Government departments and other bodies. Responses were submitted to the Department for Education's Circular on sex education, the Government's Task Force to Review Services for Drug Misusers, the Department of Health's consultation paper on short-term placements, and OFSTED's revised Framework for school inspection.

Publications: **ChildAIDS** newsletter, the only regular UK-wide publication on children and HIV, covered a wide range of topics including child sexual abuse, mother-to-child HIV transmission, and working with the media, as well as news about developments in the field. Forum information sheets were produced on 'Research in progress on children and HIV in the UK', and 'Respite care for families affected by HIV/AIDS', and a summary of current research, development and practice was published as a National Children's Bureau **Highlight**: Children and HIV.

Enquiries: The Forum dealt with over 500 enquiries from all parts of the UK, covering a wide range of legal, ethical, social, clinical, policy and practice issues.

Steering Group: The Forum's steering group was expanded in 1994/95 to make it representative of a broader range of geographical and professional interests. Its current membership is as follows:

Anne Weyman, Chair (National Children's Bureau), Janice Funnell (Barnardo's), Emma Colyer (Body Positive), Graham Sutterby (Broad Street Project), Trisha Plummer (Blackliners), Sarah Morton (Children in Scotland), Catriona Williams (Children in Wales), Dee Donnelly (East London Childcare Initiative - currently on maternity leave), Lorraine Hoare (Health Education Authority), Chris Batty (Leicestershire County Council Social Services Department), Naomi Honigsbaum (European Forum on HIV/AIDS, Children and Families), Derek Bodell (National AIDS Trust), Jean Lovie (Newcastle Social Services HIV/AIDS Project), Clare Tickell (Phoenix House), Stephanie Elsy (Positively Women), Dr Lorraine Sherr (Royal Free Hospital), Diane Melvin (St. Mary's Hospital).

HIV and AIDS: children's voices

Children's Voices is an exhibition of writings, paintings and other work by children about how they feel about HIV and AIDS, and about their experiences of living with HIV and AIDS. It will include work by children with HIV, by children who have a friend or relative with HIV, and by other children.

On 3 October 1995 the exhibition will open at London Lighthouse for several weeks, and will then be displayed elsewhere in England, Scotland and Wales.

If you are working with any children who might wish to contribute, or if you are interested in displaying the exhibition, please contact Neil Orr at the Forum (0171 843 6057).

Barnardo's report estimates number of affected children

Data on both children and adults infected with HIV is collected centrally, but no comparable information is available for children affected by HIV; that is children who may not be infected themselves but are living with the impact of HIV in the family.

No time to waste: the scale and problem of children affected by HIV/AIDS, by John Imrie and Yolande Coombes, represents the first serious attempt to estimate the numbers of children affected by HIV in the UK. Commissioned and published by Barnardo's, the study uses a model developed by the authors at the London School of Hygiene and Tropical Medicine.

The model, as the authors acknowledge, is limited to estimating the numbers of children whose mothers have HIV. Briefly, statistics are available for the numbers and ages of women tested positive for HIV. Figures are also available for the average number of children born to women of different ages within the general population. By combining these two sets of figures (along with some other data), the authors estimate that:

- there are more than 3,000 children affected by HIV in the UK; the authors project that this will rise to over 4000 by 1997;
- the majority of affected children live in either the London area (more than 1800 children), or in Scotland (600+);
- almost 60% of affected children are under 10-years-old, with the five to nine age group the largest;
- there are approximately 500 children whose mothers have died from AIDS.

The report recognises that this model 'is likely to provide a conservative underestimate of the population', since the estimate does not include various groups of affected children such as:

- children of men with haemophilia and HIV (there are known to be around 450 such children);
- children whose fathers have HIV, but whose mothers are uninfected. For instance, gay and bisexual men make up more than 60% of UK HIV cases. Of these 13,600 men, an unknown number have children (in one cohort study of gay and bisexual men, 9% had children);
- children with a sibling with HIV, rather than a parent. Again, many young gay men with HIV have brothers and sisters who are still children.

Beyond these groups there is an even harder to quantify population of children in close relationships with people with HIV beyond the immediate family. Uncles, cousins, family friends, neighbours, and so on, may not have parental responsibility for these children, but their illness or death can still have a major psychological impact.

In addition it is believed that there are many women infected with HIV who have not as yet been identified, with children likely to be increasingly affected in the future.

Despite the limitations of the model, the authors feel that it still 'provides a useful indication of the substantial number of children who will require some level of statutory and voluntary sector services and informal care'. The report goes on to look at what sort of services children and families need. Barnardo's make a number of recommendations including prioritising 'the provision of direct, practical help to affected families', making clear plans for the future care of children, and providing better support for older children and adolescents.

The report is available from Barnardo's Child Care Publications, tel. 01268 520224, price £8.50.

Forthcoming Forum publications

The Information guide for parents and carers of children affected by HIV *is to be published jointly by the Forum with Positively Women and the Paediatric AIDS Resource Centre later in the year. The author, Christine Hogg, has consulted with groups of parents and carers about their information needs. The guide will provide practical advice on what sort of support is available in relation to children, how to access it, and what to expect from it. The discussion paper* ***Children's rights and HIV*** *will also be published in 1995, covering such areas as HIV testing, consent to treatment, discrimination, and education.*

HIV statistics

By 31 January 1995, there had been 721 reports of children being born to HIV positive mothers in the UK (446 in the Thames Regions, 119 in the rest of England, Wales, and N. Ireland, and 156 in Scotland). Of these, 291 are known to be infected, 222 are uninfected, and 208 are of indeterminate status. These figures only include children born to mothers after they have been diagnosed with HIV and do not include all affected children (see above article).

In addition 298 children (aged 14 or under) in the UK have become infected with HIV via infected blood or blood products, and three more have become infected in undetermined ways. Out of a total of 592 confirmed cases of HIV in children aged 14 or under, there have been 132 deaths. 240 of these are now aged 15 or over, or were at the time of death.

National Study of HIV in Pregnancy, March 1995; Public Health Laboratory Service Quarterly AIDS and HIV figures, 27 January 1995.

The experience of foster carers looking after children affected by HIV

Jane Mounteney carried out research on the experience of foster carers while studying for an MSc Social Work. Here she summarises some of her main findings.

This small scale study focused on foster carers' perceptions of placements, beginning with preparation and training, then pinpointing specific areas during placement such as communicating with foster and birth children about HIV/AIDS, confidentiality, ill-health and treatment, stress and support, and concluding with the placement ending. Questionnaires were completed by 28 foster carers with experience of looking after children affected by HIV, from both Scottish and English authorities.

The placements

The children looked after were either infected or otherwise directly affected by HIV. However, the reasons given for the placement were not necessarily HIV related. 39% of the carers reported that the child's placement was primarily related to HIV status, 43% partly related to HIV, and 18% due to other factors including parental neglect, abuse and imprisonment.

There were frequent changes in the nature of placements, often reflecting changes in the health or circumstances of birth families. Four of the placements which began as short term turned into long term, because for instance the child's birth parent became too ill to take him back. A further three placements resulted in adoption by the original short term carers, as did one long term placement.

There was a very high rate of transracial placement for black children. Five (56%) of the nine black children were placed with white carers. Data for this study was collected in 1993, since when there has been a more concerted attempt to recruit black carers, so there might have been some improvement here.

Information needs

Although most carers felt that they had been given detailed or adequate information before the placement, they also voiced some concerns: 'One important piece of information was not given - the child's ethnic origins!'. One carer observed: 'There is a fine line between adequate information and maintaining parents' right to confidentiality - I was not given enough information on the parents' social background and medical situation'.

Confidentiality

Maintaining confidentiality - 'The loneliness of not being able to tell as one might if a child had leukaemia or was a Down's Syndrome child' - was identified as stressful by seven of the carers. Carers talked of the 'big strain of not being able to say anything about hospital visits every few weeks and about why they looked so weak' and of being 'worried in case he had an accident and bled at playgroup or other people's homes and I would have to use gloves without explaining why'.

There was a discrepancy between the number of people the agency suggested a foster carer told about the child's HIV status and who in the event the carer chose to tell. 16 (56%) admitted that they had told more people than had been suggested. 13 carers told their own children, although this had been suggested by their agencies in only 7 cases (86% of the carers had other children living in the home at the time of the placement). One carer said that 'We talked about reasons for the child being in care and discussed issues around the life-style choices of the parents (IV drug use) in a non-judgemental way. Also basics around health precautions for HIV - body fluid spills etc.'. Not all carers felt able to communicate in this way: 'I would have liked to have talked with my oldest, but could not as the foster children knew nothing about HIV'.

Communicating with the foster child

79% of the carers had not discussed HIV with the foster child, usually because the child was too young (almost half were under two years of age). With older children there were still barriers to communication: 'At first he was too young - now I'm not sure how to approach it without him telling his classmates'.

Those carers that had talked with the foster child about HIV had been quite creative in the methods used; these ranged from discussion with older children, use of specialist literature, play, story telling, drawing, and memory store. One carer explained 'He's only two and a half, but I'm using a lifestory book to help him start to understand about his illness'.

Stress

The greatest source of stress for carers related to the health of the foster child, mentioned by 13 carers. Carers highlighted the stress caused by waiting for blood test results, accompanying a child to hospital for treatment, and worrying about 'the fact that the child might not survive into adulthood'. One carer also mentioned 'coming to terms with not putting every cold down to HIV'.

Seven carers cited contact with birth parents as one of the most stressful factors in caring for the child, in particular experiencing a parent becoming progressively ill: 'We are used as substitute parents, particularly to Mum. She has become very dependent on us, phoning very frequently (approx. eight phone calls per day). We also feel we need to be constantly available'.

Despite the stress, most of the carers were positive about the placements. 26 of the 28 carers said that they would be prepared to foster another child where HIV was an issue.

NATIONAL FORUM ON AIDS AND CHILDREN

no. 4

infoSHEET

Working with families affected by drug use and HIV

In October 1994, the George House Trust in Manchester hosted a National Forum on AIDS and Children meeting on working with families affected by drug use and HIV. The meeting featured accounts by women drug users with HIV, and perspectives from workers in both community and residential drugs' services. Some of these contributions are included in this information sheet.

Following this meeting, the Forum submitted comments to the government's Task Force to Review Services for Drug Misusers, raising some of the key issues that emerged in the meeting.

It was argued that in planning, funding and providing services for drug users, it is important to take into account the fact that many drug users have children, and that drug services have a role to play in ensuring that the needs of children as well as parents are met. This may involve helping families to access other services, or in some cases direct work with the children, for example where children are staying with parents in a residential establishment. Drug workers need appropriate training and support in order to do this work.

In addition, unless child care needs are adequately catered for, many adult drug users will be unable or unwilling to access drug services. There are few residential rehabilitation services which enable children to stay with their parents, and funding may not be available even if there are places. Community-based services also need to be aware of child care needs. For instance clinics with inflexible appointment times may not be suitable for drug users who have to take and collect children from school.

Women drug users' experiences

Gaynor Driscoll is the policy and development manager for Mainliners, which works with and for people affected by HIV/AIDS and drug use. Here she presents a number of accounts by women 'trying like everybody else to create a good, solid home for their child' while having to deal not only with the effects of illness and drug use, but also poverty, homelessness, domestic violence and the unsympathetic attitudes of professionals.

Marilyn:

'I'm a 27-year-old HIV positive woman. I have been using drugs since I was quite young. I have been married and divorced, leaving me with a lovely daughter and a habit. When I had to attend hospital as an in-patient I was given a room of my own. The nurses were really freaky. I was given my own everything. I explained that I'd never had hepatitis but it made no difference. On discharge I was given a letter for my health visitor which I opened. It simply stated HIV risk in very bold letters. Next day I went to the hospital outpatients only to be told yes, I was HIV positive, give it a couple of years and you'll be dead. It was my twenty-first birthday, I had a three year old daughter. I also had a fantastic mother and stepfather without whom I wouldn't have made it to here. Six years on and many incidents since, too many to mention, things have improved greatly. I have had problems with stress, but I now practice yoga, aromatherapy and have changed my diet. I made the decision to live and to make life as good as I can for my daughter. I do not have time to think about my illness. What the hell is the point of waiting around to die.'

Helen:

'I was diagnosed two years ago with HIV. I had become very ill. My daughter was six then. I am still using street drugs. My daughter spends some time with her grandmother, otherwise she is with me. I can't really talk about my problems, they just seem impossible to deal with. My daughter fends for herself most of the time. She is very sensible. She often cooks for me. She is beginning to have problems at school. I suppose I can expect a visit soon, who knows what will happen then. Nobody has bothered ever listening to me. I haven't got the nerve to ask for help. Perhaps I will soon.'

June:

'I caught hepatitis B when six months pregnant and ended up in hospital. All I could do was cry - I thought I'd damaged the baby. I got treated like an alien. One doctor would not hold my son, because he didn't have any gloves on. There was a big red star on my door, I was in a side room. I didn't have HIV, or at least I didn't know it then. I got pregnant again but decided to have it terminated. They took a blood test to test for HIV. When I was about to leave hospital, waiting to be picked up, a nurse came into my room and said 'Your result's back. It's positive'. She walked out again. I cried my eyes out. I didn't know anything at all about HIV. My boyfriend was tested and he was also HIV positive. He was shattered when he found out. He became violent and angry. My boyfriend is now dead. That was two years ago. My son is six. I haven't had a partner since, and I sometimes feel very lonely.'

Karen:

'Well I've moved ten times in as many months. I'm in and out of bed and breakfast with my two children, aged 18 months and four-years-old. I had to leave my husband. I started off in a women's hostel, but they didn't like me taking drugs there. I only took enough to keep me straight. I had to leave. I never told them I was HIV. My children are both OK. It's hard to get a proper address. My borough doesn't even seem to recognise that I've got special needs. I am getting help now though, and I should be getting somewhere soon. I can't cope with the harassment in B'n'Bs - they all know about me.'

Ann:

'When I first met my husband I was symptomatic. Shortly after my first illnesses, I found out I was pregnant. My son was born with antibodies and he still has them now. He does not eat properly, and is not putting on any weight. He is being tube fed most nights to build him up, and help him fight off any illness. Because of my HIV illness, I had a Caesarean section, and I was too weak to walk. My son was in the special care baby unit in an incubator for six weeks going through withdrawal for methadone and valium. My boyfriend would wheel me to see him every day... I've had the virus for nine years now. I will go on fighting, I will not quit. I hope my son will lose his antibodies. I would love to live long enough to see him have children.'

Addiction is physically painful, and many drug users feel that they do not get sufficient medication to help them with this. People who have cancer have appropriate morphine treatment as pain relief; why is it so different because somebody's got a label of 'drug user'?

Susan:

'I have two kids, a boy aged four, and a girl aged two. I have been using heroin since I was 16. I am now on a script of 50 mg a day. My nurse, social worker, and drugs worker have all asked my doctor to increase my script to 75 mg but to no avail. I wanted an increase to help me take my son to school, to help me function, to help me go out shopping. I sometimes feel I can't handle this, and feel like giving up. None of my family are near, although I've got a good husband who understands and helps with everything. I just wish we could all go out together. If I got my script put up, there's a lot more I'd be able to do.'

Many drug services are becoming less accessible and relevant to women with children. There is an expectation on women that they can behave like they haven't got children, that they can attend a meeting at the drop of a hat without considering the care or the needs of their child.

Liz:

The drug dependency unit we have used started to change the way they work. People who used to get a pink form for two weeks* now have to go to the clinic at 8:30-9:00 am three days a week to have their methadone given to them there. But the problem lies with people like Louise who has to get her girl to school and then do a Linford Christie to get to the clinic to get her medicine. But as she was late by about seven minutes, due to having difficulties getting her daughter to school, she was not given her methadone. She had to go two days without her supply. This meant to maintain her ability to care appropriately for her child, she had to go out and score smack again. She did not like it, and was extremely upset. We all thought that was a bit out of order. I mean aren't these people paid to help us out, not make life more difficult than it is already.'

(* methadone prescription)

Mainliners, 205 Stockwell Road, London SW9 9SL (tel. 0171 737 7472, fax. 0171 737 3361)

Supporting families

Lynda Shentall, North Manchester Community Drugs Team

Drug users with HIV are often said to be a hard to reach group, and if this is the case their children are an even harder group to reach. The negative experiences of drug users can discourage them from seeking support. Recently we heard of a case where a woman was in a local hospital with her baby, and she had abscesses on her legs from injecting. When she was found to be HIV positive, the staff stopped dressing her abscesses, and it was left to another patient to help her. That woman is someone that we will probably lose contact with and if hospital staff had taken a better approach then she could have been tapped into services for herself and her baby.

There can be many people working with a family, while other families are very isolated. The important point is where support is focused. In a two parent family, both parents may be positive but one may be particularly supported. If that parent dies, what happens? When someone has died whole families can drift out of contact. It is important to build in both adults, but this can be difficult. Within family support women seem to be the ones that get help but with drug services it often seems to be the opposite; in a couple the man would be more likely to come forward than the woman. Woman tend to perceive that the children will be taken from them if they approach an agency for help.

Services need to examine that and look at the whole family's needs, adults and children. If there is more than one child in the family, their needs may be very different. Some children may be HIV positive and others not. Older children may be more aware of the situation and may have taken on adult responsibilities in terms of the younger children.

In relation to residential services, one problem is that funding for children to stay with their parents can be very difficult to arrange. Funding for adults comes out of the community care budget, but it should be children's services which pay for children to accompany parents to rehab. However if the child is not 'at risk',-children's services may refuse to pay out of their budget. We are fortunate in Manchester to have secured a small budget to send children to rehabs with their parents.

Lynda Shentall is chair of the George House Trust, and is a social worker with North Manchester Community Drugs team, Tel: 0161 682 0757

Working with children at Brenda House

Eddie Winship, Aberlour Child Care Trust

Brenda House in Edinburgh is a short term, residential rehabilitation facility for mothers with drug or alcohol misuse problems and their children. It is run by an organisation called the Aberlour Child Care Trust, which now has about 19 projects.

Brenda was a Glasgow woman drug user, who said to Joy Barlow (our project manager) that if a mother has got a drugs problem and wants to do anything about rehabilitation there isn't anywhere she can go with her children. As a result Brenda House was opened in 1989. Brenda unfortunately didn't live to see Brenda House come into fruition but it is some sort of memorial to her.

Brenda House is not, nor has ever pretended to be, primarily a HIV/AIDS resource and being HIV positive or indeed being tested, is not part of the admission criteria for Brenda House. Nevertheless bearing in mind the Lothian situation where HIV is a concern, it's a big part of the day to day running of Brenda House. All of the families that we work with are affected if not infected by the virus.

We have a number of groups for women at Brenda House, including a group on parenting looking at what is happening with women and their children.

Our assistant project leader, along with one of the children's playworkers sits down with each mother and looks at an individual care plan for each child and their individual development.

We have a weekly children and play session, where all the mothers and all the children and as many members of staff as possible do something together. The main reason is to help the mothers see that they can enjoy spending time with their children and doing childish things.

Our work with the children really centres around helping them in the first instance to realise that they are in a safe and a caring environment and one in which they can feel free to express themselves. We do this in different ways.

In the mornings when the mothers are in groups and the children are in the playroom we look at organising both individual and group play for them. I think it is easy to get carried away with the whole idea of play therapy when quite often all the kids want to do is to have fun. However, if there is something particular happening for a child, such as a visit to the doctor or a visit to the dentist, we might look at some sort of play around that to help them understand what is going to be happening to them and what it means.

During the school holidays we try to take the children and also those of ex-residents away for trips as often as possible. We have a caravan in a fishing village and we take children down there on occasions.

A lot of things happen spontaneously with the children. I think that is important as well. You can organise and put things into frameworks and so on but there has to be room for spontaneity. I remember on one occasion we were talking about a particular girl and the children started asking questions. We ended up talking for about 45 minutes about HIV/AIDS. The children ranged from three to about 14, and there was an amazing amount of understanding, including talking about death and about what that meant to them.

The way we work with any children who may be HIV positive is absolutely no different from the children who we are fairly sure are not. All kids have fears and anxieties that they need to talk about and sometimes these fears are to do with school or nursery and so on. Sometimes they have got to do with the mother and how she is, and sometimes they are about themselves: 'Am I ill, what is going to happen to me?'. These fears should be allowed out and children should be allowed to talk about them. The questions are who does the telling, what should be told and how should the telling be done?. The mother has to play a very important part in that process and in these decisions. We as professionals have no right to take these kind of choices away from her. We feel that we have to provide a safe and protected environment for the mother and for the children that enables and empowers them to talk about the things that worry them.

In addition to the time spent with other children in the group, each child in the house gets from the staff a 'special person'. This isn't anything as formal as a counsellor, it's a member of staff that the child can spend time with, feel safe with, get to know and feel free to talk to. Rather than this member of staff being appointed, the relationship tends to develop freely until the member of staff says that they would like to be a particular child's special person, and then we check this out with the mother and it goes on from there. I am a special person for a lad who is now eight and who has been away from the house for three years now but I still manage to spend time with him about once a month.

We have two link workers who maintain contacts with ex-residents, and we also try to pair every woman up with a volunteer as a befriender when they leave the house.

Some volunteers are involved in befriending the mother which extends to befriending her children as well. Other volunteers are involved in befriending individual children and one prime example was a seven-year-old girl whose mother was really quite ill. She was used to sometimes being at home with her mother, sometimes being in the hospice with her mother but sometimes being with various foster families because her mother was in hospital on her own. The volunteer was the only stable adult in the girl's life.

Brenda House, 7 Hay Road, Niddire, Edinburgh EH16 4QE (0131 669 6676).

Getting to the Point

Tom Aldridge (Health Education Authority, 1993)

Getting to the Point *is a modular series of training manuals on drug use and HIV, with accompanying video. One of the eight volumes focuses on 'Family work, drug use and HIV', with themes including the impact of HIV on the family system already stressed by drug use, and working with secrecy in the family.*

Details from Health Education Authority, Hamilton House, Mabledon Place, London WC1H 9TX.

Working with drug users in London

Lorraine Hewett, Director, Stockwell Project

The current HIV statistics in Britain show that approximately 1,500 injecting drug users have been infected by HIV in England and Wales, and another 1,000 in Scotland. Many of these are young people. In the UK over 10 per cent of injecting drug users with AIDS are under 25, and 13 per cent of women injecting drug users with AIDS are under 25. It has been estimated that there are up to 200,000 injecting drug users in England and Wales. So there are a lot of people at risk, at least a quarter of these are women, and most of these are of child bearing age.

It is also a fact that people are still sharing needles. Needle exchanges are not sufficiently accessible; they tend to attract older people. We need to find imaginative ways of attracting younger people into needle exchanges.

A lot of chronic active drug users may want to give up drugs but many may not and they may not be able to. Projects like us accept that our client group will continue to use drugs and we define our professional intervention as maximising their health care and trying to maintain the support for them and their families.

Different family patterns

The Stockwell Project's main client group is chronic drug users who are unlikely to give up drugs in the near future; at any given time about 80 of our caseload are HIV positive, many of whom have children.

In our experience, different communities of drug users in London have different family patterns. We have got large numbers of Irish and Italian drug users attending (we have specific services aimed at these groups), and the other group that is quite highly represented is Scottish drug users.

Many of the Italians are from middle class backgrounds and highly educated. We have about 50 HIV positive Italian clients, nearly all of them men aged 30 or over. Very few of them have children around; if they have children they tend to be back at home with the family.

With the Scottish clients it seems to be common for the men to come to London first and then their partners may join them later. The children are as likely to be staying behind with relatives in Scotland as they are to be coming down to London. With a lot of our Scottish male clients, the partners have already died and the children are back in Scotland with their grandparents or other relatives.

The picture is different with Irish drug users. They are almost all from Dublin, they are working class, they have often been in Mountjoy prison, and in fact some of them became infected in Mountjoy prison. They tend to be young (many of our Irish clients are under 25), and they commonly come over with their partners and often with the children as well, arriving at the service together in great immediate need. They like to take their children around with them because they are frightened that someone will take them away.

Housing is a major issue for recent arrivals and for families affected by HIV. Currently we have several new families from the Republic who have not even been accepted yet for temporary bed and breakfast. Those families are then sometimes criticised for appearing chaotic and not being able to perform all the tasks that they are supposed to.

Services

There is a tendency to ghettoise HIV drug users and their families, by excluding them from HIV and mainstream services. The facts are that many mainstream services have tacit but very effective methods of discouraging drug users from attending. In London there are HIV centres where we have never once succeeded in referring a client, and there are hospital clinics where none of our clients has ever had a good outcome.

Services are often not accessible to drug users with children. For instance there has been no real increase in the number of child beds in rehabs in the last ten years and some that were instituted have disappeared. Those that do exist tend to be expensive.

Methadone maintenance programmes have been shown to reduce needle sharing, HIV rates and other health problems, but provision is still very patchy and many drug dependency units keep patients stranded in dingy waiting rooms which are very unwelcoming to mothers with children.

Support for parents

It is important to make the point that many families cope and do well. It is also I think important to note that a persistent feature of many drug users' past is their own childhood deprivation. They may have been underparented, neglected, and abused; there have often been parental alcohol, drug abuse or mental problems, or criminality. They have often been in emotionally confusing family structures with multiple surrogate parents and long periods in care.

They often need help with parenting skills because they haven't been parented themselves and they are caught up in the cycle of deprivation and poverty. Our clients really want to be good parents, but a lot of them need help and support. There are times that the worker has to say 'we need to work with you on this issue because you haven't got this right'.

In our own agency, we have taken on more of a child protection role than in the past. Quite a lot of the time we are involved in working directly with child protection teams in social services to try and keep families together and identify support, but at times our agency will ask for protection orders.

The final point I want to make is that if statutory services seriously want to reduce harm and assist positive drug users and their children, they should accept that drug users should be seen when they turn up, wherever they present. Services should try and deliver as much care as possible in one go, rather than make appointments for them to go somewhere else. Accept unpredictability and try to work with it.

The Stockwell Project (1-3 Stockwell Gardens, London SW9 ORX, tel. 0171 738 7784) is a health service funded drugs service in south London.

SCODA Guidelines

SCODA's 'Guidelines for good practice' state that 'Drug use by parents does not automatically indicate child neglect or abuse... Each family should be assessed individually'.
Included in ***Drug using parents and their children*** *published by SCODA and the National Local Authority Forum on Drug Misuse. SCODA (Standing Conference on Drug Abuse), Waterbridge House, 32-36 Loman Street, London SE1 0EE (0171 928 9500).*

NATIONAL CHILDREN'S BUREAU
The powerful voice for the child

This InfoSheet is produced by the National Forum on AIDS and Children, National Children's Bureau, 8 Wakley Street, London EC1V 7QE.

Scotland

Scottish teachers' union teams up with Children in Scotland to put children affected by HIV on agenda

by Sarah Morton, Children in Scotland

A partnership between Children in Scotland, the Scottish national agency for those working with children and families, and the Educational Institute Scotland (EIS) the main teachers union with over 48,000 members in nursery, primary, secondary and further education, resulted in a one-day conference addressing the issues for teachers when working with children affected by HIV. This was an opportunity to look beyond curricular approaches to HIV prevention, and consider the complexities of working with affected children and their families. About half of the teachers attending knew of affected children in their class or school.

'Government imposed changes in education and other centrally driven priorities have meant that issues of care, and concern for individual children have all too often been neglected in recent years' said EIS Education Convenor George MacBride, chair of the conference. 'There is now a need to redress this balance, and issues around HIV and AIDS are of increasing concern for members'.

Joy Barlow, of Aberlour Childcare Trust told delegates that there was a need now to 'normalise' the issue of HIV. 'We've got to step back from believing that there is something very difficult or different about HIV'. Schools can play a crucial role in this process.

One of the main concerns expressed by teachers was the issue of confidentiality and secrecy when a pupil or a member of a pupil's family is HIV positive or has AIDS. Some children will see their teacher, or another person at school as a place to ask for help, as this may be the only contact they have with adults outside the family.

The delegates said that one of the most valuable aspects of the day was the opportunity to hear from professionals outside education working with affected families. Further events of this type, perhaps on a regional basis, were suggested. The conference was held on a Saturday, allowing teachers to attend without having to arrange for cover, or get permission.

Children in Scotland and the EIS launched a leaflet at the conference which provides background information for teachers on where to go for help when working with a child or family affected by HIV. This includes guidance, education department contacts, and HIV agencies who are able to provide help, and it will be distributed to all schools in Scotland.

New publications

Children's Rights and HIV: a handbook for working with children and their parents

by Kathleen Marshall, Jacqueline Mok, Sarah Morton, Joan Over and Hazel Robertson

An HIV-infected toddler bites another at nursery, breaking the skin; a sexually active 14-year-old in care is thought to be HIV positive; the child of an HIV positive mother wants to know why people keep visiting the house and whispering; 'does my mum have AIDS?' she asks a volunteer befriender.

What rights do the children in these scenarios have? What rights and responsibilities do the adults have - the nursery teacher, the care worker, the volunteer, the mother? This handbook, written by a multidisciplinary working group, discusses children's rights issues through a series of case studies, and uses questions to address rights issues in similar situations. Training and policy recommendations that come out of the studies are also discussed. Set in a context of the UN Convention on the Rights of the Child, and the legal framework of Scotland, the booklet could however be used by workers outside Scotland as the bulk of the work is in discussion form.

This is a very helpful, easy to use document which addresses the complex and difficult issues around children's rights in a sensitive and supportive manner.

Price £2.50 per copy from Children in Scotland.

Forthcoming: Young Carers in Families Affected by HIV: a study based in Lothian Region

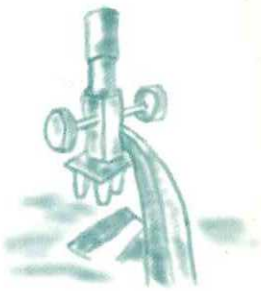
by Heidi Alexander

Young carers are often overlooked by service providers, but those caring for a parent with HIV or AIDS are even more invisible due to the stigma surrounding the virus. The findings of this survey suggest that professionals can play a key role in determining the quality of young carers' experiences and perhaps whether these young people are identified at all. Professionals involved with young carers are in a position to influence public policy and political attitudes by taking equal and overt account of children's rights and needs as children and as carers.

Further information from Deborah Gray, Children in Scotland, Princes House, 5 Shandwick Place, Edinburgh, EM2 4RG. Tel: 0131 228 8484

research

CLINICAL TRIALS UPDATE



by Neil Orr

Trials are continuing to look at how well anti-HIV drugs are tolerated and how well they work in children with HIV infection. This article describes the latest developments in the trials being organised under the auspices of PENTA (Paediatric European Network for Treatment in AIDS), as well as recent US results.

At present the main focus remains on a family of drugs known as 'nucleoside analogues', which aim to prevent HIV replicating itself. Nucleoside analogues being tested in children include zidovudine (AZT), didanosine (ddI), dideoxycytidine (ddC) and now lamivudine (3TC), a new experimental drug being developed by Glaxo.

PENTA 1: early or late treatment?

The main aim of the PENTA 1 trial is to find out whether it is better to start treating children with AZT early on in the disease or to wait until symptoms develop. To date, over 180 children have been enrolled into the trial from 12 countries (including Canada and Brazil as well as European countries). The independent Data Monitoring and Safety Board has reviewed the trial and given its approval for it to carry on. It is expected to continue for at least another two years (for a description of PENTA 1, see the article in ChildAIDS no.2).

Combination therapy

The benefits of AZT do not last forever, partly because strains of HIV which are resistant to AZT may develop after taking the drug for a while. In the treatment of cancer and other illnesses, taking combinations of different drugs at the same time has been found to be more effective than using one drug at a time. Trials in adults and children are looking at how useful different combinations of anti-HIV drugs might be.

The PENTA 3 study is comparing the combination of AZT plus ddC in children with taking AZT alone, to find out which is best tolerated. A new trial, PENTA 4, is due to start later this year assessing the safety and tolerability of 3TC in different combinations with AZT and ddI. Trials of 3TC in adults suggest that it is less toxic than other similar drugs. Unlike AZT for instance, it does not damage bone marrow cells, although some side effects have been seen including headache, fatigue, diarrhoea and insomnia. No data is available yet on its effect on symptoms or survival.

In the US, more than 800 symptomatic children have been taking part in a trial (ACTG 152) in which some children have taken AZT, some ddI and some a combination of both drugs. In February 1995, the Data Monitoring and Safety Board overseeing the trial announced that those children taking AZT alone have not performed as well as the other two groups in terms of side effects, symptoms, development and survival. Further information will be available after the trial finishes at the end of August (see *Lancet*, Feb.25 1995, p.511 and *Lancet*, Apr.29 1995, p.1115).

For the time being AZT will continue to be the first-line therapy for children with HIV infection in the US and Europe, though this will be reviewed once the full results of ACTG 152 and similar trials in adults are available later this year.

Reducing the dose

Trials of AZT in adults found that the recommended daily dose could be reduced without making the drug less effective. A US trial (ACTG 128) has found that the same applies with children. In this study, children who took half the dose taken by other children (360 compared with 720 mg/m^2 day) had the same clinical outcome. Doctors taking part in the PENTA trials can now prescribe a lower dose than that previously given.

A further issue highlighted by the ACTG 152 trial is the need to develop more child-friendly formulations of drugs. Many children in Europe have found ddI unpalatable and have been resistant to taking it. For the US trial a special formulation of the drug was developed, but this is not as yet widely available.

Information about the PENTA trials is available from the MRC HIV Clinical Trials Centre, UCLMS, Mortimer Market Centre, London WC1E 6AU.

Child clears HIV

Paediatricians in Los Angeles have reported a case of a child infected with HIV apparently clearing the virus from his bloodstream. The child was born to a mother with HIV, and was found to be infected with HIV by two PCR tests at 19 and 51 days of age. However at 12 months of age the child was found not to have HIV, and numerous subsequent tests have confirmed this. The child is now five-years-old and healthy.

The most widely used HIV test detects the antibodies a person's immune system produces in response to the virus. Children are born with their mothers' antibodies to HIV, even though most are not infected themselves. If the child is uninfected, these antibodies will clear within 18 months. This doesn't mean that they've cleared the virus, because the virus was never present in the first place.

This case is different. Polymerase chain reaction (PCR) testing looks for genetic material from HIV which will only be present if children are infected themselves. What is significant is that PCR testing detected the presence of the virus itself in the child's bloodstream, but subsequently the child apparently spontaneously cleared HIV. It is not known how or why this might have occurred, and it is debateable how important this finding is. Even if the case is as it appears, there is unfortunately no reason to believe that children infected with HIV can rid themselves of the virus except in a tiny number of exceptional cases. No such cases have been seen so far in the UK.

See T.J. Bryson et al, Clearance of HIV infection in a perinatally infected patient, New England Journal of Medicine, vol.322, no.13, March 30 1995, pp.833-8.

resources

Women Like Us: Positively Women's survey on the needs and experiences of HIV positive women *(1994)*

Based on interviews with 75 women living with HIV, this research covers women's experiences of a range of voluntary and statutory services. Over half of the women were mothers, and the report includes a valuable section on children and child care. A major concern for many women was how to talk to their children about HIV. While 77.5% of women had not disclosed their HIV status to their children, the majority wanted to do so in the future but were concerned about the child's ability to understand the information and keep it confidential, as well as the lack of support for children once they have been told.

Two-thirds of the women were not receiving any home care, and only 30% had support with child minding. A third of the women were concerned that their child(ren) might be taken into care; the authors note 'it is often assumed that HIV positive mothers who are anxious about social services are drug users, but African mothers may not understand the role of social services' (80% of the women interviewed were African).

The report is priced £5 plus postage, and is available from Positively Women, 5 Sebastien Street, London EC1V 0HE (tel. 0171 490 5501).

Memory Box

Y touring's Memory Box, written by Pete Johnson, is a theatre in health education programme exploring the impact of AIDS on the family. Aimed at nine to 13-year-olds, the play centres around two children coming to terms with the illness and ultimately death from AIDS of their older brother.

Although the play does dispel some myths about HIV transmission along the way, its primary focus is broader than HIV prevention, dealing very powerfully with such issues as prejudice and coming to terms with loss and separation. Y touring have performed the play at schools throughout the UK, using post performance workshops to give children a chance to explore and reflect upon their own feelings.

Details from David Jackson or Michelle Gilliver, Y touring, 10 Lennox Road, London N4 3NW (0171 272 5755).

Positive Practice: a Health Visitors Association guide to caring for families and children affected by HIV/AIDS

Robin Gorna (1994)

This book is aimed at health visitors, school nurses and practice nurses, and covers the basic facts about the virus and its transmission, guidance on safer sex and drug use, sex education, working with affected families, and professional issues such as confidentiality.

£5.95 (£4.95 for HVA/MSF members) from HVA, 50 Southwark Street, London SE1 1UN (tel. 0171 378 7255).

HIV and AIDS in children: a guide for the family

Rebekah Lwin, Candy Duggan, Diana Gibb (2nd edition, 1994)

Revised edition of the Great Ormond Street guide for the parents of children with HIV, answering such questions as 'How can I prepare my child for coming to hospital?' and 'How can I keep my child well'.

£2.50 from Rebekah Lwin, Department of Psychological Medicine, Great Ormond Street Hospital for Children, London WC1N 3JH.

The Terrence Higgins Trust has published several booklets recently. **Consider this...** aims to help women decide whether to take a test for HIV, particularly during pregnancy. **Women with HIV: your benefits, housing and legal rights** is a comprehensive guide which includes information about children. **Young gay men: a guide to coming out** includes advice on relationships, safer sex, and so on.

Available from: THT, 52-54 Grays Inn Road, London WC1X 8JU (0171 831 0330).

The family and HIV

Robert Bor and Jonathan Elford, eds. (Cassell, 1994).

*This collection of articles (many of them previously published in the journal **AIDS Care**) takes a broad overview of the impact of HIV on the family. Challenging the notion that 'family is solely determined by blood relationships', it is guided by Carol Levine's definition of family members as 'individuals who by birth, adoption, marriage or declared commitment share deep, personal connections and are mutually entitled to receive and obligated to provide support of various kinds to the extent possible, especially in times of need'. In this context, the social support networks of, for instance gay men or drug users, can be understood as particular types of families.*

Several of the articles focus specifically on children. There is some interesting material on African families, a Canadian study of the needs of carers of children with HIV, while Miller, Goldman and Bor outline a family systems approach, discussing a case study of the impact of secrecy on a family with a child with haemophilia and HIV.

Children and HIV/AIDS: community support and family placements – a guide for staff and volunteers

Leicestershire County Council Social Services Department (1994)

The aim of this guide is to explain the options available to parents and children affected by HIV, with explanations of the law, policy, and different forms of support including private and local authority fostering, facilitated placements with relatives and friends, and so on. While much of the information is locally specific, this publication might provide a useful model for elsewhere.

Available from: Service Manager (HIV/AIDS), Leicestershire County Council Social Services, County Wide Services, Sub Office, Gipsy Lane, Leicester LE5 0TD (tel. 0116 2460460, ext. 2591)

The latest edition of the **National AIDS Manual's AIDS Reference Manual**, *includes a new section on children and families written by Maria Lui of Positively Women, covering such areas as telling children about HIV and AIDS, HIV testing, and arranging for children to be fostered.*

Details from NAM Publications, 52 The Eurolink Centre, 49 Effra Road, London SW2 1BZ.

events

SEPTEMBER 1995

18th–20th

Peer led approaches to working with young people on substance misuse and HIV, *Cheltenham. Residential course, details from Youthlink Wales (tel. 01222 885711).*

28th–29th

Children and HIV: a multi-disciplinary approach, *Edinburgh. Residential course designed to promote good practice in the care of children affected by HIV (£150 including accommodation and all meals). Details from Paediatric AIDS Resource Centre (tel. 0131 536 0806).*

OCTOBER 1995

5th

Supporting children and young people through grief, loss and bereavement, *London. Barnardo's conference, details from Stacey Hartshorn (tel. 0181 5508822)*

6th

Integrating HIV issues into child protection training: a seminar for child protection trainers, *Stirling. Details from Fiona Wager, Children in Scotland, (tel. 0131 228 8484).*

10th

Sex education in schools: working towards good practice, *Sheffield. Organised by the National Children's Bureau with the Sex Education Forum and Sheffield Centre for HIV and Sexual Health. Details from the Conference Office, National Children's Bureau, (tel. 0171 843 6000).*

12th

Women and children with HIV and AIDS, *London. Organised by Course & Symposium Office, RPMS Institute of Obstetrics and Gynaecology, Queen Charlotte's and Chelsea Hospital, (fax 0181 741 1838).*

25th

Families with HIV: approaches to management, *London. Course focusing on counselling skills. Details from Teaching Administrator, AIDS Counselling, Social Care and Prevention Unit, Clinic 8, Royal Free NHS Trust, (tel. 0181 830 2820).*

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family, society, and so on. For example if you want to be treated like an adult you have to behave like one. HIV/AIDS issues are not treated differently and especially so because of its relation to sex. When working with African children, understanding their position in the family hierarchy will help to work out a more appropriate approach to their service needs.

African children as carers

Care and support of family members is the responsibility of the entire family and especially the female members. It is not unusual for children to look after their parents from as early as seven years. Likewise, older children may practically have to look after young ones as this is a value that is instilled in the majority of African children. This may conflict with childrens' rights in Britain but it has to be put into its proper perspective with an understanding of the different cultures.

A good example is one of an eight-year-old who, after being taught her family values, recorded twice in her school diary that she was worried about her six-month-old niece. She went on to say that her younger sister was her responsibility but now that she was ill, she didn't know what to do. Her teacher was so worried about this enormous responsibility for the eight-year-old pupil that she summoned her parent to get an explanation. It took a few hours to convince the teacher that the pupil was not personally looking after the baby but that it was just an African value instilled in the young to grow up with a spirit of togetherness within the extended family system.

Children's immigration status

Children's immigration status depends on that of their parents. Since many African people's immigration status is uncertain, such as students, asylum seekers, visitors, and so on, this has an impact on children especially in terms of long term planning to meet their needs.

Poverty

Related to the above is the fact that some parents such as visitors, students and illegal immigrants, are not allowed recourse to public funding. Asylum seekers will only get a percentage of what is considered as survival benefits. As a result of this families live in absolute poverty and are unable to provide good nutrition and recreation for their sick children, and may not access services for fear of their children being removed, discrimination and prejudice against them and even deportation.

Recommendations:

- There is an urgent need to improve monitoring and collect statistics about African children and their characteristics, so that sensitive and appropriate services can be developed for African children.
- All those working with African children should be trained to develop a better understanding of cultural differences and life experiences of African refugees and asylum seekers, in particular in order to work effectively with the families in addressing the children's needs.
- Emphasis should be put on working with families instead of individual children. This will give a clearer picture and understanding of the children's background. There is a need for clearer and unified strategies and policies to address the needs of both affected and infected children within the existing system.
- Joint working on assessments between social and health workers and community groups to share information about cultural issues pertaining to African children infected or affected by HIV/AIDS.
- There is also a need to develop support services for children bearing all the above in mind. We need more places like the Mildmay Family Centre and these facilities should try as much as possible to make the services appropriate, for example providing African food, encouraging African workers who are able to understand children's behavioural differences, and so on. This is not just for the children, but will also encourage parents to access these services for their children, and help them to understand and eventually benefit from them.

This article is based upon a presentation to the National Forum on AIDS and Children meeting, 31 March 1995. Josephine Namusisi, Blackliners, Unit 46, Eurolink Centre, 49 Effra Road, London SW2 1BZ (tel. 0171 738 5274)

World AIDS Day Conference 1995

Children's participation in HIV services: needs, rights and cultural diversity

Thursday 30 November 1995, London

National Forum on AIDS and Children with the National Children's Bureau and the European Forum on HIV/AIDS, Children and Families

The theme of World AIDS Day 1995 is 'shared rights, shared responsibilities'. This major conference will apply this theme to children by looking at how child-centred working can be implemented in practice in the HIV field. It will look at how children's participation can be facilitated in different services, and at the various cultural, legal and professional factors favouring or inhibiting a recognition of children's needs and rights.

Details from Conference Office, National Children's Bureau, 8 Wakley Street, London EC1V 7QE (tel. 0171 843 6042).